



# Introduction

Your Colorectal Team will have discussed the possibility of changes to your bowel function after your rectal cancer surgery. This booklet is designed to give you more information on why these changes occur and what you can do to help manage them.

After rectal cancer surgery, most people experience some changes in how their bowels function. Common symptoms include needing to open your bowels more often than before, needing to get to the toilet more urgently than before, not feeling you have fully finished. It is important to remember these changes are usually very manageable and that they will also improve over the weeks after your surgery. However, it is likely that your bowel habit long-term will never quite be as it was before your surgery and we will help you understand why this happens and what you can do to help.

If you need further information about managing your bowel function, please contact your local Colorectal Nurses for more personalised help and advice.

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# How going to the toilet used to work before surgery

To understand why your bowel may work differently after rectal cancer surgery, it is helpful to know what your rectum did before surgery and how surgery will change it.

Most adults take bowel control for granted and give it little thought except for the few minutes a day that are spent emptying the bowel on the toilet. However, bowel control is a complex process which is not fully understood. It involves delicate co-ordination of many different nerves and muscles.

The function of your large bowel (colon) was to absorb water from the waste that was inside your bowel and turn your waste material into stools (poo). Your rectum is the last part of the large bowel.

Before surgery, your rectum acted as a temporary storage chamber which was designed to stretch to accommodate bowel motion. When your rectum was full, it set off messages to your brain to let you know that you needed to open your bowels. Below your rectum is the anal canal which is approximately 3-4cm long. Within your anal canal you have a complicated nerve supply which helps your body to tell the difference between flatus (wind) and stool. The pelvic floor and anal sphincter muscles help you hold on to your bowel motion until it is convenient for you to find and use a toilet.

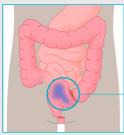
# What happens to your rectum during surgery?

To remove the rectal cancer you will have had an operation called an **anterior** resection, also called a **Total Mesorectal Excision** or **TME** for short.

The operation involves removing a section of your rectum and large bowel, as you can see in **Diagram 1**. The main reason for this operation is to make sure your cancer is removed completely.

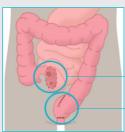
The amount of rectum removed depends on exactly where the cancer was.

### Diagram 1



Diseased or affected portion of the intestine is removed

Cancer



Remaining sections of the intestine are surgically connected back together

Temporary stoma

**Anastomosis** 

# Why do some people need a temporary stoma (ileostomy)?

Your colorectal nurse or doctor will have discussed with you why you need a temporary ileostomy.

An ileostomy is a stoma formed from small bowel (ileum). The surgeon will bring a loop of your small bowel out through a hole that the surgeon will make on the surface of your abdomen. Your waste will pass out of your ileostomy and be collected in an external pouch (called an ileostomy bag). The waste produced is usually a thick liquid or semi-solid consistency.

In due course, your ileostomy should be reversed (or closed) during another, smaller operation. Then instead of passing stools into a stoma bag, you can go back to anus and back passage.

You will have your ileostomy for at least three months. It might be much longer if you need chemotherapy after your surgery.

# What changes can happen to my bowel function after my stoma is reversed?

Having an anterior resection will change the structure and function of your large bowel and rectum. This will alter your bowel function. The changes to your bowels will be most noticeable in the first few months after your surgery. It is important to realise that your bowel will never be quite the same as it was before your cancer operation. With time, you will adjust to a 'new normal' bowel habit:

- The removal of your rectum, which acted as a storage chamber, will
  mean that you cannot hold as much stool as before. This means that you
  will go to the toilet more often than before; this is called increased bowel
  frequency. You might need to go to the toilet again within a short time; this
  is called clustering.
- Immediately after surgery and for a few weeks, your colon may not work
  as well as it used to. This means that it does not absorb as much fluid from
  your waste as it used to. This can cause you to have loose stools.
- Surgery can damage the anal sphincters or the nerves that help them to work. Your anal sphincters are important for bowel control. This means that when you have the feeling to go to the toilet it might be with greater urgency than before. You may find you have to rush to the toilet; this is called urgency.
- Surgery might also damage nerves that help you decide if what is in your bowel is stool or wind. This means that you may initially not be able to tell what is in your bottom and people often choose to sit on the toilet before seeing if it is stool or wind ready to come out.
- Surgery can occasionally cause narrowing inside the bowel (called a stricture) and restrict the stool coming out. This can cause the stool to come out thinner. If this is a problem the surgeon can investigate to see if this needs to be treated.

# What are the common bowel symptoms I may experience?

After your surgery, you may experience some common bowel symptoms.

Below is an explanation of some of the terms and symptoms your healthcare professional might discuss with you:

#### Frequency

Opening your bowels more often than before surgery

#### **Urgency**

Having little or no warning of when you need to go to the toilet

#### Incontinence

Leaking stools without your knowledge

Being unable to control your bowel motions or wind

#### **Tenesmus**

Where you have a feeling of constantly needing to pass stools, despite the bowel being empty of stool

#### Sore skin

Your skin may become sore around the back passage area, from frequent wiping or leaking stool

If after reading this booklet you feel that you need more specialist help ask your specialist GP to make a referral to see someone.



You might need to be referred for specialist assistance if your bowel problems have not got better by three months after your operation.

Your specialist GP can refer you to a specialist nurse who can help you with bladder and/or bowel problems.

# What can I do to help manage changes to my bowel function?

You may be feeling a little disheartened at reading the possible changes that can occur after your surgery. However, other patients report that being forewarned helped them to cope much better when problems occurred.

Now that you know what might happen, it is useful to know how to cope with these bowel problems if they occur.

In being prepared, you will hopefully manage any changes more easily and with less distress.

## After surgery



- Try to keep a positive outlook.
- Remind yourself that it takes time for your bowel to adjust to the change after surgery.
- Remember, your bowel function will continue to improve for up to two years.

# Good eating habits

After your surgery you may find that your appetite isn't as good as normal. You might not be able to eat a normal portion size. You may lose weight; some people welcome weight-loss but not everyone. Your eating habits should settle into a routine in the weeks after your operation and this will help to settle your bowel function as well. Some foods may cause you problems initially and may need to be avoided for a few weeks before trying them again. In the first few weeks after surgery try and eat small amounts more often during the day. Some patients report that they avoid eating during the day so that their bowels are not so active. This can cause other problems, such as weight-loss or feeling tired, lethargic and irritable. If you do not eat regularly, it will take you longer to get over your surgery. It will also take your bowel longer to adapt to the changes made by your surgery.

#### Low fibre foods

Should be eaten for the first few weeks after your operation. Food that has a lot of fibre includes fresh fruit and uncooked vegetables. Low fibre foods include white versions of bread, pasta and rice. Fibre can make your stools looser and may give you wind. A few weeks after your operation you can slowly increase the amount of fibre in your diet. Once you know your bowels can cope with these changes you can experiment with your diet a bit more. If you find that a particular food upsets your bowels, cut down on this once again and then try and re-introduce it after another few weeks. Try to re-introduce troublesome foods several times before excluding them from your diet.

#### Sorbitol

Is found in sugar-free foods, sweets and chewing gum. Sorbitol can lead to you having looser stools, bloating and wind. If loose stool, bloating and wind is a problem for you, try and reduce your intake of foods that contain sorbitol.

Ask your GP to refer you to a dietitian if you would like more specialist help.



# Good drinking habits

#### Caffeine

Can cause you to have increased bowel activity and loose stools. Caffeine can be found in coffee and tea as well as energy drinks and soft drinks such as cola. It is best to keep your intake of caffeine down in the first few months after surgery, especially if you have increased bowel activity and loose stool.

#### Alcohol

Particularly beer, lager and cider can also cause you to have loose stool, bloating and wind the day after you drink them. Therefore, it is best to restrict your intake, particularly in the first few months, especially if you are experiencing loose stool, bloating and wind.

## Fizzy drinks

Can cause wind. So if you are experiencing wind keep the amount of fizzy drinks you drink to a minimum or exclude if your wind is really bothersome.

# Good toileting habits

It is important after your operation to establish good toileting habits. These include how you sit on the toilet, when to listen to the urge to go to the toilet and when to try to resist this urge.

It is important that you do not sit and strain heavily or sit for long periods on the toilet. You should not sit for longer than 10-15 minutes at any one time.

To help your bowels to work properly, check that you are sitting on the toilet correctly. See **Diagram 2** below to show you the right position to be in on the toilet to encourage your bowel to empty your stool completely. You also need to be relaxed

If you are not sure whether you need to pass wind or stool, you may feel the need to visit the toilet just in case. Over time you should be able to re-learn which sensation means there is wind to release and which means this is a call to pass stool.

You might feel the need to go to the toilet but when you do nothing is passed. This is because of the heightened sensitivity in the bowel and will usually settle within a few weeks of surgery.

To make toilet access easier you can carry a **No Waiting Card**. These are available from Coloplast, as well as other organisations. You can also use disabled toilets with a **Radar Key** (which can be purchased from Disability Rights UK).

You can gain more confidence about how long you can hold on before you have to go to the toilet without having an accident. You can try holding on to your stool for a little while when it is safe and you are near (or on) the toilet. You can help by using a distraction and keeping calm.

## Diagram 2



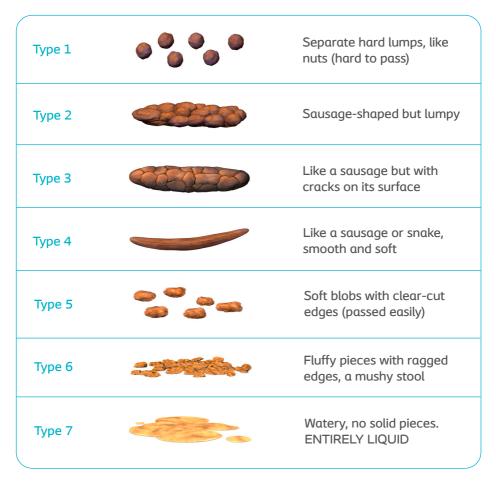
#### **Evacuation Posture**

- · Knees higher than hips
- Lean forward and put elbows on knees
- Bulge abdomen
- Straighten your spine

# The Bristol Stool Chart

The Bristol Stool Chart below highlights the variation of stool type you will have. After surgery, it is not uncommon to find that your stool type is different to how it used to be before your operation. Your stool type may also alter over the course of a week.

An ideal bowel movement is regarded to be Type 4. After surgery, if Type 3 to 6 is achieved and you are happy with this that is fine too.



Adapted from The Bristol Stool Scale (Heaton et al 1992)

# **Exercise**

Your pelvic floor and sphincter muscles can become weak as a result of surgery. It may be that you had weak muscles before the treatment but could manage to keep control of your bowels. Now, since your surgery, this might be more difficult.

Carrying out some strengthening pelvic floor exercises may help you to be able to control your bowels more easily. Stronger muscle strength will mean that when you feel urgency you can consciously tighten your anal sphincter to prevent leakage of wind, liquid or even solid stool. Like any other muscles in the body, the more you use and exercise them, the stronger the sphincter muscles will be (see Useful Resources at the end of this booklet for more information).

# Skin care

If you have frequent bowel motions, diarrhoea or accidental leakage (faecal incontinence) you may get sore skin around the back passage. Sore skin can be very uncomfortable and distressing. Taking good care of the skin around your back passage can help to prevent sore skin from developing.

## The following tips may help you:

- After a bowel action, always wipe gently with soft toilet paper or use moist toilet paper
- Discard each piece of paper after one wipe, so that you are not re-contaminating the area you have just wiped
- Whenever possible, wash around your anus after a bowel action
- Don't be tempted to use disinfectants or antiseptics. Just use warm water for cleaning your skin
- If you do use a barrier cream, use just a small amount and gently apply it to your skin
- Have your sore skin looked at by your healthcare professional if the discomfort remains

# Medication

If you have any concerns about using any of these medications, please speak to your Colorectal or Stoma Care Nurse.

#### Loperamide (Imodium)1

Loperamide is a drug which is very useful if you have loose stools. Loperamide is also helpful if you need to go to the toilet frequently. It is advisable for you to make changes to your diet before you consider trying Loperamide. You can access a leaflet called Explaining how to take Loperamide (Imodium) from St Mark's Hospital (see Useful Resources at the end of this booklet for more information).

You may have used Loperamide before as it is what people take abroad in case they have a spell of diarrhoea whilst on holiday. The packaging will say that you cannot exceed a certain dose and not to use long-term. However, this advice is for people who do not know what is causing their diarrhoea. It is perfectly safe for you to use Loperamide for as long as it helps. Loperamide comes in capsule and liquid form.

Loperamide works by slowing down the passage of stool through your colon. This means you can absorb more water from your stool, which helps form your stool and reduces the amount of times you need to go to the toilet. Loperamide may also help with urgency and can reduce the intensity of the gastro colic reflex.

## Fybogel and Normacol

Fybogel and Normacol are bulking agents to try to bulk up your loose stools, particularly if you frequently need to pass small amounts of stool. Bulking agents come as a sachet of powder which is dissolved in a glass of water. You can take a bulking agent once or twice daily.

Bulking agents can also be used in conjunction with Loperamide. Before taking both medications together ask to speak to your Colorectal Nurse to get further advice.

# You can buy these medications from a pharmacy.

However, you may be entitled to free prescriptions if you are a UK resident or if you have a medical card in the Republic of Ireland. Ask your Colorectal Nurse or pharmacist for more information.



# What happens if my bowel function doesn't improve?

The vast majority of patients who have undergone an anterior resection will be able to get back to work or move on with their life after adjustment to their 'new normal' bowel function. You should be no different. However, for a small group of patients, their bowel function can take longer to settle into a habit that is manageable.

### When to ask for help?

A few weeks after your operation think about your bowel function. If your bowels are still causing you problems please speak to your Colorectal Nurse who can give you advice and help to manage these problems. Problems might include leakage of stool from your bottom or having to urgently get to the toilet. Your Colorectal Nurse can suggest changes to your diet as well as using medication

If after a few weeks of trying new ways to manage your bowel changes, without enough benefit to you, it might be necessary to see a Specialist Nurse. You may need to be referred by your GP, but here are some ideas of what is available to help your bowel problems:

### Biofeedback / Specialist Bowel Dysfunction Service / Continence Specialist

You may benefit from a referral to a biofeedback / specialist bowel dysfunction service. One way this group of healthcare professionals can help your bowel problem is to teach you to re-train your bowel. As you gain more control over your bowel you should feel more confident when going out.

# Peristeen® Plus Transanal Irrigation (TAI)

Peristeen Plus is a transanal irrigation system that helps people manage faecal incontinence and/or constipation. It has been designed for people who suffer from faecal incontinence or chronic constipation and for those who have to spend a long time on bowel management procedures due to neurogenic and functional bowel dysfunction.

Peristeen Plus is an effective water-based treatment. It works by introducing water into your bowel, using a cone catheter, which is inserted into your anus. The water, along with stool in the lower portion of the bowel, then empties into the toilet.

Peristeen Plus enables you to decide when and where you empty your bowel. Many people benefit greatly from being able to establish a regular and predictable bowel management routine. Using Peristeen Plus routinely to regain control of your bowels can give you the confidence to live life the way you choose and enjoy the activities that are important to you.

A commitment to regular use is key to success and Coloplast® Charter's dedicated team of Care Quality Commission (CQC) rated Outstanding telehealth specialists are available to support you in establishing confidence with Peristeen Plus. They speak to people who use Peristeen Plus every day so are in a great position to pass on tips, advice and the wisdom of other users' experience.

Peristeen Plus use may be short or long-term, depending on your needs. It should only be instigated after discussion with your Colorectal team and it is important to wait for at least 12 weeks after your original operation.

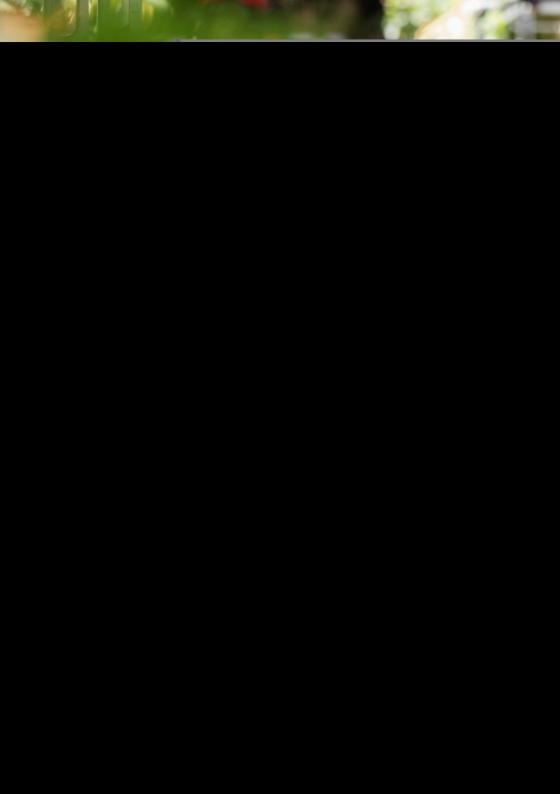
Peristeen Plus has been recommended for adoption in the NHS; please refer to www.nice.org.uk/guidance/mtg36 for this guidance.





Coloplast Charter Best Start™ for bowel patients - dedicated telehealth product and clinical support to help patients succeed with Peristeen Plus. CQC Inspected and rated Outstanding.







# Key messages

We hope you have found the information in this booklet useful. Do remember:

- Most people find their bowel symptoms do improve after rectal cancer surgery; most improvement occurs in the first three months
- After three months there is likely to be some additional improvement but this will be at a much slower rate
- However, if your bowels are bothering you, causing you embarrassment and/or stopping you from doing the things you enjoy, then please seek help
- Nevertheless, it is important to accept that your bowel habit is unlikely to be quite as it was before surgery
- Dietary changes often help
- Medication can play a useful role in reducing frequency, urgency and improving evacuation but seek professional advice first
- Practising pelvic floor exercises on a regular basis may improve the strength of your muscles which promote continence and thus control
- There are a range of other lifestyle factors that can be considered so please do seek help from your specialist nurse, GP or cancer team

# Useful resources

You may be interested in visiting the following websites for further information and advice regarding bowel symptoms and management:

#### Bladder and Bowel UK

www.bbuk.org.uk

### **Bladder & Bowel Community**

www.bladderandbowel.org

#### **Bowel Cancer UK**

www.bowelcanceruk.org.uk

#### Disability Rights UK

www.disabilityrightsuk.org

#### Macmillan Cancer Support

www.macmillan.org.uk

#### NHS - What are pelvic floor exercises?

Available from: www.nhs.uk/common-health-questions/womens-health/what-are-pelvic-floor-exercises/

# St Mark's Patient Information Leaflet Explaining how to take Loperamide (Imodium) leaflet

Available from: www.stmarkshospital.nhs.uk/wp-content/uploads/2014/05/Explaining-how-to-take-Loperamide.pdf

If you're in the Republic of Ireland:

# Irish Cancer Society

www.cancer.ie

If you would like more information on Peristeen Plus, please visit:

www.coloplast.co.uk www.coloplast.ie







